Desire for Information and Involvement in Treatment Decisions

Lung Cancer Patients' Preferences and Their Physicians' Perceptions: Results from Okayama Lung Cancer Study Group Trial 0705

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Introduction: This study explores patient preferences for involvement in lung cancer treatment decisions and the extent of concordance between the views of patients and physicians on decisional roles. The impact of demographic and psychosocial characteristics on the decisional role of patients is also examined.

Methods: Patients with relapsed non-small cell lung cancer who were candidates for a phase II trial of erlotinib monotherapy were recruited. Patients were interviewed after they had learned of their relapse and the treatment decision had been made but before pharmacologic intervention.

Results: Most of the 28 participants were married, had a smoking history, and were well educated. They reported moderate levels of depression and anxiety. Initially, 14% of the patients reported a preference for active decision making; later, 29% believed that the primary responsibility for the treatment decision had been theirs. Only 54% of the patients agreed with the physician's assessment of how the treatment decision was made ($\kappa = 0.31$; test of symmetry, $p = 0.23$). The depression score was significantly associated with a patient's preferred level of control ($p < 0.01$).

Conclusions: The limited concordance between patient preference and perception and between patient and physician perceptions regarding how the treatment decision was made suggests that physicians should more accurately identify patient preferences by directly asking patients at the beginning of each clinical encounter.

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The past 2 decades have witnessed increased research in patient preferences for information and decisional roles in the treatment process, and a shift to a more patient-centered approach to healthcare delivery. This movement, often termed shared decision making, emphasizes a more active, participatory role for patients and a more tailored approach to patient education by healthcare providers.[1–3]

A growing body of literature demonstrates that decision making shared between patients and providers can result in a variety of benefits, including improved patient satisfaction and clinical outcomes.[4–11] Considerable attention has focused on identifying patient preferences and the extent to which these preferences are met in patient-provider interactions. These issues have been extensively examined with breast cancer patients[12,13] but not fully with lung cancer patients.

We investigated the degree of desired involvement in treatment decisions of a sample of lung cancer patients who were enrolled in a phase II trial of erlotinib therapy, and we explored the extent to which these patient preferences were met. We also examined whether anxiety and depression play a role in decision-making preferences.

METHODS

Patients

Between January and December 2008, Japanese patients with non-small cell lung cancer in six institutes affiliated with Okayama Lung Cancer Study Group who relapsed to the first-line or second-line chemotherapy participated in a prospective phase II trial of erlotinib monotherapy.[14] The phase II trial included the current study as a preplanned subset analysis. Of the 30 patients, 28 consented to this subset

TABLE 1. Control Preferences Scale: Three Parallel Versions

Patient Preference Scale	Patient Perception Scale	Physician Perception Scale
I prefer to make the final selection about which treatment I will receive.	I made the final decision about which treatment I would receive.	The patient made the final decision about which treatment she or he would receive.
I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.	I made the final selection of my treatment after seriously considering my doctor's opinion.	The patient made the final decision about which treatment she or he would receive after seriously considering my opinion.
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.	My doctor and I shared responsibility for deciding which treatment was best for me.	I shared responsibility with the patient for making the final decision about treatment she or he would receive.
I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.	My doctor made the final decision about which treatment would be used but seriously considered my opinion.	I made the final decision about which treatment the patient would receive, after seriously considering the patient's opinion.
I prefer to leave all decisions regarding my treatment to my doctor.	My doctor made all the decisions regarding my treatment.	I made the final decision about which treatment the patient would receive.

In this study, the scale was collapsed to three levels: mostly patient for the first and second options; shared decision making for the third; and mostly physician for the fourth and fifth options of the patient preference, patient perception, and physician perception scales (see *Methods*).

TABLE 2. Clinical, Psychosocial, and Sociodemographic Characteristics

No. of patients	28
Sociodemographic characteristics	
Median age (range), yr	67 (35–88)
Gender (male/female)	22 (79%)/6 (21%)
Smoking history (yes/no)	20 (71%)/8 (29%)
Marital status (married/unmarried)	24 (86%)/4 (14%)
Education (posthigh-school graduate/high-school graduate or less)	17 (61%)/5 (18%)[a]
Clinical characteristics	
Tumor histology (adenocarcinoma/other)	19 (68%)/9 (32%)
Performance status (0/1–2)	6 (21%)/22 (79%)
Prior chemotherapy regimens (<2/≥2)	12 (43%)/16 (57%)
Prior platin use (yes/no)	20 (71%)/8 (29%)
Respiratory comorbidity (yes/no)	5 (18%)/23 (82%)
Psychosocial characteristics, median (range)	
HADS anxiety score	6 (0–12)
HADS depression score	6 (0–16)

[a] Data were not available for six patients.
HADS, Hospital Anxiety and Depression Scale.

analysis; the other 2 declined to participate. This study was approved by the institutional review boards of all participating institutes.

Study Flow

The main outcome measures of this study were three parallel versions of a control preferences scale (Table 1).[15] All the study patients were interviewed on recruitment to the study,[14] which was after they had learned of their lung cancer recurrence and the treatment decision had been made, just before therapy began. Patients were interviewed using questionnaires that assessed sociodemographic characteristics, psychosocial constructs, and decisional-role outcome measures (patient perceptions; Table 1). Sociodemographic variables included date of birth, marital status, and education. Patients also completed the Hospital Anxiety and Depression Scale (HADS),[16] which screens psychiatric problems in medically ill patients by using a 4-point, 14-item self-assessment scale to measure 2 factors of psychologic distress: anxiety and depression. Physicians attending the patients were also interviewed to assess their perceptions.

Data Analysis

Differences among the groups were evaluated using Fisher's exact test and the Kruskal-Wallis equality-of-populations rank test. To determine where deviations occurred between patient perceptions before and after the treatment decision and between patients' and physicians' perceptions, κ statistics and a test for symmetry were applied to assess agreement and discordance. For these analyses, the patient preference scale was collapsed to three levels, similar to those of previous studies (mostly patient, shared decision making, and mostly physician; Table 1)[17–19] because of the sparse number of responses at the tails. Statistical analyses were conducted using STATA version 10 software (College Station, TX). Values of $p < 0.05$ (two sided) were considered statistically significant.

RESULTS

Patient Characteristics

Table 2 summarizes the patient characteristics. Most were married males with a smoking history and high education level. With regard to the clinical information, most had adenocarcinoma and a history of platin use.

Patients posted relatively low baseline HADS scores for both anxiety and depression. The median score was 6 for each, with a range of 0 to 12 for anxiety and 0 to 16 for depression. In general, women reported relatively high levels of anxiety in communicating with their physician (median scores: 8 for females versus 5 for males; $p = 0.03$), whereas the depression score was comparable between female and male patients (median: 7.5 for females versus 6 for males; $p = 0.35$). The 28 patients were attended by a total of 17 physicians (15 male and 2 female), whose ages were in the twenties to forties (median, thirties).

TABLE 3. Patient Preferences Stratified by Clinical and Sociodemographic Characteristics

Factor	Patient Preferences			*p*
	Active	Shared	Passive	
Age (yr)				
≥67[a]	2 (13)	9 (60)	4 (27)	>0.99
<67[a]	2 (15)	8 (62)	3 (23)	
Gender				
Male	3 (14)	13 (59)	6 (27)	>0.99
Female	1 (17)	4 (67)	1 (17)	
Smoking history				
Yes	2 (10)	12 (60)	6 (30)	0.52
No	2 (25)	5 (63)	1 (13)	
Marital status				
Married	4 (17)	13 (54)	7 (29)	0.31
Unmarried	0	4 (100)	0	
Tumor histology				
Adenocarcinoma	3 (16)	13 (68)	3 (16)	0.26
Others	1 (11)	4 (44)	4 (44)	
Performance status				
0	0	5 (83)	1 (17)	0.54
1–2	4 (18)	12 (55)	6 (27)	
No. of prior chemotherapy regimens				
≥2	1 (7)	9 (64)	4 (29)	0.75
<2	3 (21)	8 (57)	3 (21)	
Prior platin use				
Yes	3 (15)	12 (60)	5 (25)	>0.99
No	1 (13)	5 (63)	2 (25)	
Respiratory comorbidity				
Yes	0	5 (100)	0	0.28
No	4 (17)	12 (52)	7 (30)	
Patient knowledge of epidermal growth factor receptor-tyrosine kinase inhibitors				
Yes	3 (23)	7 (54)	3 (23)	0.49
No	1 (7)	10 (67)	4 (27)	

Data are presented as *N* (%).
[a] Median age.
EGFR, epidermal growth factor receptor.

Decision Control Preferences

Seven (25%) of the patients favored a passive role in treatment decision making, whereas 14% favored an active role, and 61% preferred a collaborative role. Preference for a passive role did not correlate with any of the clinical or sociodemographic factors evaluated (Table 3). In contrast, patient preferences were affected by their depression status, with median depression scores of 7, 7, and 3 for the active, shared, and passive roles, respectively ($p < 0.01$; Figure 1*A*). The groups also differed in anxiety status, with median anxiety scores of 3, 7, and 3, respectively ($p < 0.01$; Figure 1*B*).

Patient Perceptions Versus Patient Preferences and Physician Perceptions

Table 4 shows that 67.9% of the patients perceived that they made the decision they had initially preferred, resulting in between patient preferences and perceptions ($\kappa = 0.48$; test of symmetry, $P = 0.10$). Table 5 contrasts the views of patients and physicians with regard to the treatment decision. Only 53.6% of patients agreed completely with those of their physicians concerning who made the treatment decision ($\kappa = 0.31$; test of symmetry, $P = 0.23$), that is, compared with the patients' perceptions of their involvement in treatment decisions, physicians tended to perceive that patients were more actively involved. There was less discordance between the patient preferences and physician perceptions with κ of 0.23 (% agreement: 46.4%; Table 6).

DISCUSSION

Our results show that the perceptions of patients and physicians with respect to their roles in treatment decisions agreed in only half of the 28 cases. In addition, two thirds of the 28 patients perceived that they made the decision in the manner they had initially preferred. These results indicate that concerns and management strategies were insufficiently discussed between the patients and physicians.

One possible explanation for the discrepancy between the views of patients and physicians regarding the patient decisional role is that the physicians based their perceptions on behavioral cues, which have been shown to be inconsistent with patient perceptions.[20,21] Physicians who want to meet patient expectations may need to ask directly about role preferences, instead of trying to discern them from opinions offered or questions asked by the patient.[12]

We also used HADS to investigate depression and anxiety status and the relationship between these states and patient preferences. First, we observed relatively low overall HADS depression and HADS anxiety scores, which were almost identical to those of primary breast cancer patients.[13] Generally, in contrast to breast cancer patients, patients with relapsed non-small cell lung cancer have a poor prognosis, with a median survival time of approximately 7 months.[22] Thus, we initially thought that the 28 patients would report higher HADS scores. Given that the general condition of these patients was good enough for accrual into the clinical trial, the HADS scores of these patients might have been lower than what we had initially expected.

Second, we showed that HADS scores may affect patient preferences. Although our data do not allow for causal interpretation, patients with passive decision-making preferences had lower depression scores, compared with patients with collaborative or active preferences. In contrast, in a neoadjuvant setting for newly diagnosed breast cancer, patients with passive role preferences had higher HADS depression scores, perhaps because patients who are depressed because of their symptoms prefer to leave their treatment responsibility to the physician.[13] Our findings are also in contrast to two other studies that found no differences in HADS scores among role preferences.[12,23] These conflicting results may be explained by differences in assessments, samples, data analysis, or ethnicity.[12,23] Further studies are needed to determine the impact of depression and anxiety on decision-making preferences.

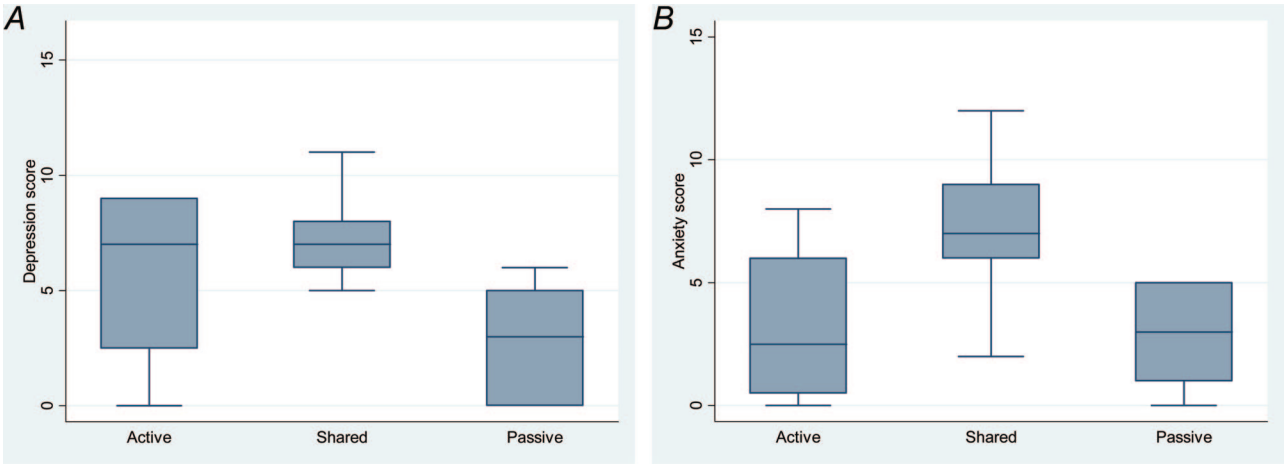

FIGURE 1. Box and whisker plots. The bottom and top of the box represent the 25th and 75th percentile (lower and upper quartile), respectively. The band near the middle of the box is the 50th percentile (median). *A,* Association between patient preferences and depression status. The higher the depression score (*y* axis), the more likely the patient is in a depressive state. *B,* Association between patient preferences and anxiety status. The higher the anxiety score (*y* axis), the more likely the patient is in an anxiety condition.

TABLE 4. Patient Preferences and Perceptions

Patient Preferences	Patient-Perceived Level of Control (*N*)			
	Active	Shared	Passive	Total, *N* (%)
Active	3[a]	0	1	4 (14.3)
Shared	5	11[a]	1	17 (60.7)
Passive	0	2	5[a]	7 (25.0)
Total, *N* (%)	8 (28.6)	13 (46.4)	7 (25.0)	28 (100)

% agreement = (3 + 11 + 5)/28 = 67.9%.
[a] Complete agreement.

TABLE 5. Patient Perceptions and Physician Perceptions

Patient Perceptions	Physician Perceptions (*N*)			
	Active	Shared	Passive	Total, *N* (%)
Active	6[a]	2	0	8 (28.6)
Shared	5	5[a]	3	13 (46.4)
Passive	2	1	4[a]	7 (25.0)
Total, *N* (%)	13 (46.4)	8 (28.6)	7 (25.0)	28 (100)

% agreement = (6 + 5 + 4)/28 = 53.6%.
[a] Complete agreement.

We have several limitations. Because there were 17 physicians attended 28 patients meaning less than 2 patients by physician, we could not sure that they provide the patients with the same information. This may influence the principal results. In addition, the sample size did not allow us to do subgroup analyses. Furthermore, the control preferences scale and the way physicians understood how patients took decisions have not yet fully been validated extensively. Thus, our results should be interpreted cautiously.

In conclusion, despite our small sample size, the HADS score, and not the sociodemographic or clinical factors assessed in this study, was associated with a preferred decisional role. The overall lack of concordance between physician and patient perceptions of the decisional context indicates a gap that must be narrowed. One reasonable and unobtrusive approach would be for physicians to directly ask about a patient's preferences at the beginning of each clinical encounter and to then check on the patient's level of satisfaction with the decision-making process.

TABLE 6. Patient Preferences and Physician Perceptions

Patient Preferences	Physician Perceptions (*N*)			
	Active	Shared	Passive	Total, *N* (%)
Active	3[a]	1	0	4 (14.3)
Shared	8	6[a]	3	17 (60.7)
Passive	2	1	4[a]	7 (25.0)
Total, *N* (%)	13 (46.4)	8 (28.6)	7 (25.0)	28 (100)

% agreement = (3 + 6 + 4)/28 = 46.4%.
[a] Complete agreement.

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